

Overview of NCTTP Research Project and Opportunities for Collaboration between SOT Recipients

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ORR Recipients Meeting

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Advancing the knowledge, technical capacities and resources devoted to the care of torture survivors living in the United States
and acting collectively to prevent torture worldwide

Outline

1. History and focus of NCTTP Research & Data Committee
2. Status update of Committee's work
3. Next and future steps, including opportunities for collaboration between SOT recipients

The Research and Data (R&D) Committee

NCTTP has had an R & D Committee for many years (initially led by CVT). Its main focus, since 2008, has been the Data Aggregation Project.

Data collected from a chart review of survivors served in NCTTP participating centers used for:

- Program planning and evaluation
- Advocacy
- Public and professional education
- Fundraising
- Research

Collecting NCTTP individual level data prepares programs to submit ORR data

Since 2008, project housed at Oregon Health & Science University (OHSU)

Project recently moved to Bellevue Program for Survivors of Torture (PSOT) with IRB oversight from BRANY

NCTTP Data Project: An Overview of Development

Agreements & IRB Structure

- NCTTP Data Use Agreement
- Investigator Agreements
- IRB Data Collection Protocol & IRB Oversight
- Data Safety Monitoring Committee

Technical Support

- Secure Electronic Data Transfer & Storage
- Data Dictionary
- Excel file - drop down menu
- Random # link to Client ID

Initial Numbers

- Over 60 individuals from 25 NCTTP Treatment Centers provided input
- At least 25 Conference calls, Many, many individual calls & letters, hundreds of emails
- 5 - 8 revisions for each IRB Document
- Obtaining “buy in” from 28 - independent centers to sign one Data Use Agreement
- Publications from this project: Authored by the Participating Member Centers

NCTTP Data Aggregation Project: Details

- Data collected FY 2008 to FY 2019 (all ORR & additional data points)

Individual data on over 17,000 torture survivors, including:

- Demographics
 - Torture history
 - Mental and physical health diagnoses,
 - Social networks
 - Functional outcomes (i.e., employment, housing, years of education, and immigration status)
- 28 NCTTP centers have submitted data since the project's inception
 - Multiple years of data for most of the survivors
 - In 2020, the NCTTP created a Data Subcommittee to revisit the project.
 - In the process of transferring all existing data to Bellevue PSOT and collecting FY 2020 to FY 2022



NCTTP Data Aggregation Project: Details

Client Data

Legal
Status at first arrival
Status at Intake
Current status
Asylee / refugee

Persecution History
Age of first torture
Location of torture
Reasons
Methods

Demographics
Age
Ethnicity
Nationality
Religion

Clinical History
Goals at Intake
Mental Health DX
Outcome measures
Blood Pressure, Diabetes

Statuses
Housing status
Access to food and clothing
Employment history
Education history

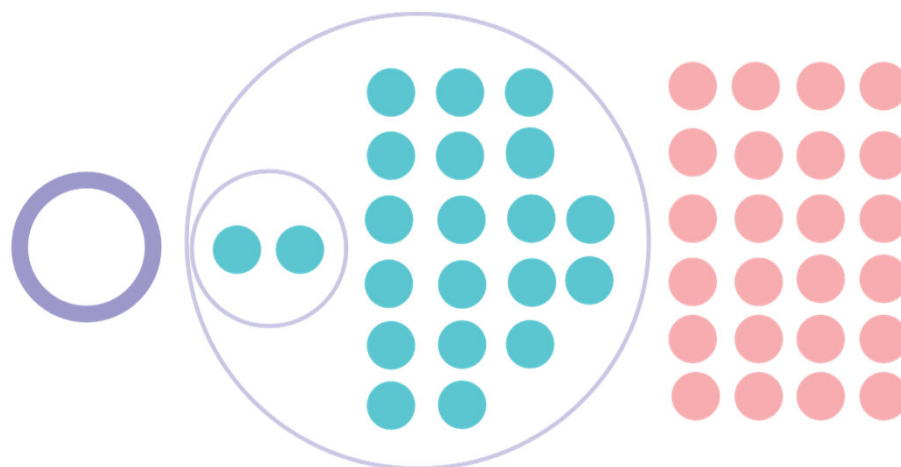
Social Networks
Spend time with family and friends
Participation in activities
Care giving
Volunteer work

NCTTP Data Aggregation Project: Details

Center Data

Center	Center Training	Center Pro Bono	Center Services
Center Name	Medical	Medical	Legal
Funding	Social	Social	Social
Clients Served Legal	Mental Health	Mental Health	Physical Health
Clients Served Social	Legal	Legal	Mental Health
Clients Served Mental Health	Education	Admin	
Clients Served Physical Health	Law Enforcement	Translation	

NCTTP Data Aggregation Project: Research Model



Individual centers can view their own data and collaborate with some – or all – other members participating in the project.

Half of all centers are not yet participating in the project.

Even if your center cannot submit all of the requested data, it can still submit a partial data set.

Characteristics of Survivors & Services

Who are the survivors represented in our data?

Survivors of torture
(many have also
experienced other
traumas)

Young children to
elders

From a wide range of
countries of origin

Diverse socioeconomic,
political, religious,
personal backgrounds

Ranging from new
arrivals in U.S. up to
many years in U.S.

Differing legal
statuses



What kind of services provided?

Wide range survivor services (some or all in house): case management, social, psychological, medical, forensic assessment, expert witness testimony, legal representation

Also: public education, training, and advocacy

Article published in *Torture Journal*

Member Centers of the National Consortium of Torture Treatment Programs (NCTTP) (2015). Descriptive, inferential, functional outcome data on 9,025 torture survivors over six years in the United States. *Torture Journal*, 25(2), 34-60. <https://doi.org/10.7146/torture.v25i2.109673>

Descriptive, inferential, functional outcome data on 9,025 torture survivors over six years in the United States

Member Centers of the National Consortium of Torture Treatment Programs (NCTTP)

Abstract

Background: The National Consortium of Torture Treatment Programs conducted a large voluntary research project among torture rehabilitation centers in the United States (US). Its goal is to fill the void in the literature on demographic and diagnostic data of torture survivors across a large country.

Methods: Twenty-three centers across the US collaborated over six years, utilizing training and making decisions via conference calls and webinars. A data use agreement signed by all the participating centers governed plans and the use of the data.

Findings: This study reports on torture survivors from 125 countries, 109 of which signed the United Nations Convention against Torture (UNCAT). Of the 9,025

seeker. At one and two years after beginning treatment, both asylum seekers and refugees reported increased rates of employment and improvements in their immigration status.

Interpretation: This longitudinal project provides basic data on a large number of torture survivors who accessed services in the US, and provides a foundation for long-term follow up on immigration status, employment status, diagnostic status, medical diagnoses, and eventually, the effectiveness of treatment for torture survivors in the US. This article shares demographic and diagnostic findings useful for informing programmatic and policy decisions. However, these findings on refugees and asylum seekers in the US may not reflect the experience in other receiving countries. Collaboration with other research-

Strengths of the NCTTP Data Project

- History of strong collaboration across consortium centers
- Large population of diverse torture survivors
- IRB oversight and data safety protocols in place
- Amassed the largest and continually expanding data set of its kind on over 17,000 torture survivors
- Potential capacity for long term follow-up of the torture survivors we treat

Special thanks to the dedicated efforts of former R & D Project Chair Crystal Riley, OHSU, and the efforts of many who have contributed over the years, including the R&D Project Committee Members as well as its Data Safety Monitoring Committee, Subcommittee, and Advisory Committee.

2020 NCTTP Data Subcommittee

Charged with presenting NCTTP ExCom with recommendations in three areas related to the R & D Committee Data Aggregation Project:

- Transparency;
- Access; and
- Questions to be posed to the OHSU IRB (the IRB of record).

Subcommittee membership

- Dani Folks, Craig Higson-Smith, Martin Hill, Brian MacMillan, and Megan Berthold (chair)

Data Subcommittee Recommended a Project With 4 Phases

Phase 1 - The initial work

- Conducting an **inventory of the status** of the R & D Project database in keeping with the technical recommendations outlined later in this document;
- Working with the OHSU IRB for project planning purposes;
- Clarifying whether the PI of the current R & D Project and OHSU personnel are committed to continued oversight of the R & D Project at OHSU; and
- If the PI and current OHSU personnel do not wish to continue with active oversight of this project, we recommend **working with the NCTTP to transfer the R & D Project to another IRB.**

4 Phases (Continued)

Phase 2 – Revise the Data Use Agreement (DUA) and associated IRB protocols to incorporate any changes to the R & D Project agreed to by the NCTTP

Phase 3 – Refining protocols and mechanisms for NCTTP member centers to request the use of R & D Project data for **ADVOCACY** purposes and for broader NCTTP advocacy.

Phase 4 - Refining protocols and mechanisms (including IRB mechanisms) for the **RESEARCH** aspect of the R & D Project (e.g., establishing a protocol agreed to by the NCTTP for using data for research in collaboration with the IRB of record)

Short- and Long-Term Tasks

Key short-term tasks:

- Finish completing all IRB applications in BRANY
- Finalize and fully execute new Data Use Agreement (DUA)
- Transfer all existing data from OHSU to Bellevue PSOT
- Collect FY2020 to 2022 data (with ongoing consultation to centers)
- Visioning & problem solving (e.g., formats & venues for presenting advocacy data, implementation issues such as barriers to submitting data)

Longer term tasks may include:

- Developing focus for expanded NCTTP research (for the whole consortium and/or for sub-groups of NCTTP centers)
- Developing protocols for use of NCTTP data by consortium members

NCTTP Data Aggregation Project: Current Status

Agreements & IRB Structure

- NCTTP Data Use Agreement has been standardized
- IRB Data Collection Protocol has been updated
- IRB Oversight – as well as investigator agreements – transferred to BRANY

Data Transfer and Security

- KiteWorks has been chosen as the tool for data transfers
- Data Dictionary and Data Collection Guide have been updated
- Excel file template for data submission has been updated
- Use of anonymous keys and de-identified data with “no PHI identifiers”
- Waiting for completion of IRB oversight before transferring the data.

Future Goals

Working collaboratively:

- Expand collection of outcome and other data relevant to program planning / management, advocacy and research
- More in-depth analysis of existing data
- Expand dissemination of findings
- Improvement of data collection and reporting processes:
 - standardization of data structures and meta-data;
 - streamlining protocols;
 - automation; and
 - including additional training resources.

Engagement of NCTTP Members and Opportunities for Collaboration between SOT Recipients

- Encourage all SOT Recipients to join NCTTP if they haven't already. Email NCTTP membership chair: director@cstnet.org
- Want robust engagement of all NCTTP programs / centers:
 - Your voice and expertise are valued and needed!
 - Want the project to yield findings and products that are useful and relevant to you! Need your involvement in shaping that.
 - Remember, we welcome your submission of data (even if you can only submit some of the datapoints, such as the ORR ones)
- Great opportunity for engagement in the R & D committee meetings (held on the 3rd Tuesday of each month)
- For specialized issues, likely will develop sub-committees or work groups and welcome participation from NCTTP members.

Collaborating as a consortium we can achieve:

1. Peer support and sharing of best practices
2. Much larger dataset that better describes torture survivors served in the U.S.
3. Opportunity to better understand what contributes to improvements in outcomes
4. Opportunity to develop in-depth research across member centers and engage survivors and the community in our efforts
5. Data can be used by all centers for advocacy, securing funding, public education, and to inform program planning and policy decisions.

Join us in the endeavor!

Benefits of Active Participation & Collaboration

Thank you to the Research & Data Committee and member centers! We look forward to our continued collaborative work in the years to come!